

Consultation response

Question 1: We would like to know in what context you are responding. Please choose one of the following:

I am responding as:

- a) an individual who experiences chronic pain
- b) a family member or carer of someone who experiences chronic pain
- c) a health professional
- d) an organisation representing people who experience chronic pain
- e) other stakeholder (please tell us in the comments box below)

Also as founder member of the Cross-party Group on Chronic Pain

Question 2: Please choose your preferred option (Chapter 2 provides details).

- Option 1 – a centre of excellence in a single location
- Option 2 – a service delivered by local chronic pain clinicians
(supported by other clinical advisors in another part of the country)
- Option 3 – a service delivered in different locations
(by a team of chronic pain specialists – an outreach or roving service)

Please tell us why this is your preferred option in the comments box below. The factors listed in Chapter 2 of the consultation paper may help you.

It will be difficult enough to find a specialist chronic pain management multi-disciplinary team to staff one new specialist pain management centre – there is no realistic chance of finding enough of those to fulfil options 2 and 3.

One centre means that all specialists would operate from one single location, facilitating communication and patient follow up as well as cross-fertilisation of ideas and experiences.

Having a centre in a single location would mean that all the specialist skills not found anywhere else would be found in one location. By definition, a 'centre of excellence' should lead the field. Also, this centre should be able to provide much more than just treatments (see below)

It would be difficult to provide residential care for patients along the same lines as the Bath centre if this service were not in a single location. (cont.)

The single location option has been tested and tried. It is more straight forward to implement and to refine than the other two options meaning that it should also be ready for intake of patients more quickly.

The option of a single centre has already been considered, evaluated and recommend by chronic pain specialists in Scotland (as far back as 2010) (see '*Developing a National Model for Chronic Pain Services in Scotland*' published by the Government in 2010)

Question 3: Are there any of the options you disagree with? (If No, move straight to Question 4.) YES

If yes, please tell us which one(s) in the comments box, and why?

Disagree with 2 and 3

Chronic pain consultations for patients with extreme and complex levels of pain need to be in person for a variety of practical, clinical and psychological reasons.

Apart from the current shortage of qualified and experienced multi-disciplinary chronic pain professionals in most regions in Scotland, it would take an unacceptable amount of time to set up options 2 and 3 (it has taken over 10 years to set up MCNs in Scotland (much simpler than options 2 and 3 and, as yet, they are not fully implemented) plus the fact that more chronic pain specialists would take a longer time and more expenses to be trained.

This doesn't mean that MCNs will not be useful and the current drive to train GPs in pain management is not necessary. They are just different – MCNs and primary care chronic pain management are general and a first point of contact for the patient – a centre of excellence specialises on difficult and extreme cases and has the best professionals in the field not necessarily found elsewhere.

Question 4: If you have other ideas that have not been covered, please tell us about these in the comments box below. You may want to include the advantages and disadvantages of each.

If we are spending a lot of money on a specialist centre, it makes sense to think of add-ons to enable the possibility of the centre generating funding and maximizing its reach.

As a planned 'Phase 2', it would be beneficial to add a chronic pain research centre (which is, incidentally, one of the functions of a centre of excellence). A good example of how this can be done is the National Institutes of Health (NIH) Pain Consortium in the USA, the Neuroscience Research and the Sydney Pain Research Unit, both in Australia and the

National Centre for Alternative and Complementary Medicine (NCCAM) in the US and is part of the National Institutes of Health (NIH). They also have dedicated funding for CAM and chronic pain research. This research service could be run in collaboration with the Chronic Pain Steering Group's Research Sub-Group.

Scotland was once a leader in the field of the neuropeptides and neurochemical research, centred at the University of Aberdeen which led to the discovery of opiate receptors. There is no reason it couldn't lead the way again and attract funding and marketing/patenting profits in the process.

Such attached research centre could also provide *independent* evidence on new therapies and techniques (including non-pharmacological interventions), some of which could reduce costs and increase effectiveness of treatments.

Collaboration with Scottish universities as well as with similar organisations abroad would probably enhance the benefits of the specialist chronic pain centre.

On a different point, there is an argument for paying special attention to the design of the centre to maximize its impact. Research shows that the actual physical space play an important part in health outcomes. A good starting point and example is the Centre for Integrative Care in Glasgow's Gartnavel General Hospital. An added benefit would be the enhanced image of the centre as an international model.

As we discussed at the first consultation meeting in Glasgow, it seems to make sense to locate the centre within the region around Perth as it is geographically centred as well as being relatively near the most heavily populated areas in Scotland.

But in very isolated areas, there may be a need for an ambulant service based in the specialist centre when required (similar to other existing health services in those areas such as dentists and so on). But, depending on how often this extra service was expected to be used, it might even be more cost-effective to fly patients in (from the islands, for instance) – plus this would project an excellent image of the Scottish chronic pain management service nationally and abroad.

The use of public transport to access the centre for those patients living in isolated areas in Scotland would probably carry the same issues as taking patients from Scotland to Bath.

(cont.)

The addition of a multi-modal (rather than just multi-disciplinary) team offering *evidence-based* non-pharmacologic interventions including Complementary and Alternative Medicine (in the same way that the Department for Veteran Affairs does in the US) would provide non-pharmacologic treatments to support those patients who are too sensitive to medication or choose to have non-pharmacologic interventions when appropriate.

One final point. There seem to be conflicting views about how many patients would be using the new specialist centre, especially when numbers are projected from Bath and Wales figures.

Those estimated numbers seem to be very small, especially when we consider the reported number of chronic pain patients suffering from “intense, highly disabling, severely limiting chronic pain” – the kind of patients using the specialist centre - is 5.6% of the Scottish population (according to *Developing a National Model for Chronic Pain Services in Scotland* published by the Government in 2010). This makes it well over 280,000 potential users.

Even if only 0.5% of those patients were referred and used the new centre’s facilities (so .5% of 5.6%), their numbers could still be as high as 1,400 – which is nowhere near the figures currently quoted. So the need for the specialist centre is much higher than expected.

Question 5: What do you think the barriers are to accessing a residential pain management service? (For example, distance away from family, work or family commitments, upfront travel costs.)

Please list as many as you wish in the comments box below and include any others that are important to you.

- Distance
- Pain itself
- Upfront travel costs
- Lack of knowledge by GP and other involved health professionals with consequential non-referral
- Misdiagnosis
- Hopelessness (as consequence of well-known pain-related mental health conditions such as depression and anxiety)

Question 6: Please choose from the list below which aspects of residential pain management services should be included in a Scottish service.

(choose as many as apply)

| | |
|---|---|
| A chronic pain assessment | X |
| Supported one to one sessions to teach coping skills | X |
| Group sessions | X |
| Residential accommodation | X |
| Opportunity for immediate carer/support provider to accompany patient | X |
| Peer support | X |
| Tailored exercise programme | X |
| Medication assessment | X |
| Other (please tell us in the comments box below) | X |

- Pleasant and comfortable space and facilities (for the reasons given above)
- Access to non-pharmacologic interventions

Question 7: Irrespective of the final service model selected, should access to the current service provided in Bath (or elsewhere in the UK) be retained for occasional use?

Yes No Don't Know (It would be good to keep options open but a well-run specialist centre providing everything that the centre in Bath provides should make it unnecessary to take patients to Bath)

Question 8: Have you previously attended, or supported someone attending a residential service outside Scotland?

Yes (please answer Question 9)

No (please move straight to Question 10)

Question 9: If you have attended, or supported someone attending a residential service outside Scotland, please tell us about any advantages and disadvantages of the experience.

Comments (box expands with text input - there is no word limit)

Question 10: If you, or someone close to you, has been offered but declined a residential service outside Scotland what were the reasons for this?

N/A

Question 11: If you wish to add any further comments on issues raised in the consultation paper or current chronic pain services in Scotland, please use the comments box below.

- There should be dedicated funding for chronic pain management in the same way that there is dedicated funding for diabetes, smoke cessation, and so on. (after all, chronic pain affects more people than diabetes and CVD together)
- Encouragement should be given to GPs to undergo training on chronic pain so that chronic pain can be first dealt with within primary care
- Clinical guidelines should be given greater emphasis and mechanisms to facilitate implementation should always be put in place – including those guidelines which recommend non-pharmacologic interventions (including CAM)
- Chronic pain patients need to be given more choices and be more empowered to share responsibility for their treatments (so, GPs need more information on specific treatments for chronic pain)
- There is a need for a chronic pain coding to be developed and fully detailed figures on chronic pain in Scotland to be made available regularly in the same way other conditions are.
- There is a need for a standard real-time patient-related quantitative and qualitative tool to measure effectiveness of systems, initiatives, guidelines and so on including cost effectiveness and adverse effects.